

ROUGHLY EDITED COPY

GOVERNOR'S COUNCIL FOR PEOPLE WITH DISABILITIES

ANNUAL CONFERENCE

"INVEST IN PEOPLE: SHARE IN THE PROFITS"

LUNCH PANEL: JOHN CARDWELL, KIM DODSON, NANCY GRIFFIN, AND
STEVE MCCAFFREY

NOVEMBER 16, 2009

11:45 a.m. - 2:06 p.m. EST

CART PROVIDED BY:

Voice to Print Captioning

1511 E. Valley Place

Dyer IN 46311

1-219-865-7837

* * * * *

This is being provided in a rough-draft format.

Communication Access Realtime Translation (CART) is provided in
Order to facilitate communication accessibility and may not be a
totally verbatim record of the proceedings.

* * * * *

>> STEVE TILDEN: Good afternoon. I spoke with you all this morning briefly. I can tell you're still all awake after lunch. So drink your iced tea. We'll get started with our panel discussion for this afternoon. If we could get your attention from the folks at front. I want to introduce the panel of lobbyists and advocates from Indiana. We're going to talk about the State of the State and share their predictions about the upcoming General Assembly session and their impact on people with disabilities.

In alphabetical order, John Cardwell, over here on my left, is the founder and director of the Generations Project and founder and president of Hoosiers First. Both projects support education and advocacy on behalf of senior citizens, people with disabilities and low income citizens.

John has chaired the Homecare Taskforce since it was initiated in 1986, coordinated the efforts that led to the passage of the 1987 bill establishing Indiana's Choice homecare program. He also drafted model systems, changed homecare legislation for the Taskforce, which was passed in 2003 as Senate Enrolled Act 2003.

John has a long history of employment and service as an advocate and lobbyist and has served on numerous boards and commissions.

Kim Dodson, on my right, is the Associate Executive Director of the ARC of Indiana. The Arc, as you know probably, is a statewide membership organization that advocates on issues important to people with developmental disabilities and their families. Along with management responsibilities, Kim's job focuses on public policy at the state and national level. Kim joined the Arc staff in 1998 as Director of Government Relations, a field she has worked at since 1992. And she served as a U.S. Congressional staff member and then with the Indiana House of Representatives, the Indiana Chamber of Commerce and as a contract lobbyist.

Nancy Griffin, on my left here, next to John, is a consultant and trainer on the Americans with Disabilities Act and is currently serving as an access consultant for SOCOA, aging and inhome solutions. Previously, as many of you know, she was the Executive Director of the Indianapolis Resource Centers for Independent Living and State Director of the AARP for Indiana.

Steve McCaffrey, on my right, is President and CEO of Mental Health America of Indiana, formerly known as Mental Health Association.

Mental Health America advocates for policies at the state and national level. Steve and his staff have been successful in

advocating for parity requirements in healthcare policies, along with a myriad of other legislative and policy changes. Parity is an issue that we talked about this morning, and it's moved tremendously by the new federal law.

Steve has been with MHIA since 1990. He is a recipient of the Webster Kefler Award for special achievement in public policy advocacy, a member of the Board of Directors of the National Mental Health America and Board Member of the American Society of Mental Health Association Professionals.

Steve has been named to the National Directory of Who's Who in Executives and Professionals and by the Indiana Journal as a member of Who's Who in Indiana Healthcare.

I'd like to start our panel discussion with John Cardwell, and then we'll go through the different folks who will make statements and then we'll have some dialogue back and forth with the people on our panel. So I'll turn it over to John at this point.

>> JOHN CARDWELL: Good afternoon, everyone. It's good to see you. It's my pleasure to be here today. It's always great to be in this conference. So many people here who have been friends of mine for many years. So it's great to be up here. It's also fun to be up here on this panel with three people I know quite well. So you probably know Nancy and I are married.

But I used to work with Steve McCaffrey, oh my gosh, about 30 years ago. And I probably have actually spent more time with Steve than with Nancy.

[Laughter]

But I have a question. Is Edward Stotts, Edward, you got the Merl Norman cosmetic thing. That's very valuable. Steve's been using Merl Norman for 20 years.

[Laughter]

No, I'll proceed, because we don't have that much time. If some of you can't understand me, it probably means you weren't born in Indiana. As a native Hoosier, I have to confess English is a second language for me. But I hope you'll tolerate me for a few minutes here.

I'm going to talk about home community-based services in the upcoming General Assembly. And I think you're going to hear several common themes from all of us in terms of the state budget being really, really tight. But one of the things that I'll emphasize -- and I think the rest of the panel will emphasize -- even though we have a tight budget, it doesn't mean things will not happen.

And one of the things that's very, very important for all of you to do is what you have done in the past, is what you continue to do, and that's be advocates for whatever cause

you're interested in and advocates for people with disabilities as a whole because without a doubt, good public policy that allows every citizen in the state of Indiana to be fully involved in civic life and community life, without a doubt that saves us money. When people can be full partners in our society, people can be full contributors, and when it's a true two-way street, that's good for everyone. And I believe and I think everyone believes it's good for the economy. So don't be shy about advocating for programs and services for people with disabilities regardless of whether or not it's a tight economy.

The second thing I want to mention overall, if you look at the history of state programs for home and community-based services, when the economy is down, states have often enacted sweeping home and community-based service reforms. Because when you really do the number crunching, you really analyze what's needed and what's most cost-effective. What you find is that letting people live in their homes and be active in the community is far, far cheaper for taxpayers than putting people into institutions.

So if you hear a politician say to you, "we can't afford it", just stand your ground. Stand your ground. Stand on his toes or roll your chair over his toes or whatever. But make the point that these programs do save money. And they enrich lives.

And it's the right thing to do.

Now, several of us have been working on some draft legislation. And I must admit: Yes, I am a lobbyist. And if you've been reading the Star recently, you might get an impression that some lobbyists have horns. I can guarantee you I have not found any horns on my head or Steve or Kim's head. And I'll confess that I have actually drafted bills and given them to legislators. But the bills we draft are bills based on what you all are telling us to do.

And the bottom line is if we as citizens don't share our ideas in words or in writing, the legislators, who's going to do it? So to begin, don't be shy about that.

But we have drafted a model bill this year which we're calling, for lack of a creative name, we're calling it Part 2 -- Senate Roll Part 382, Part 2, to try to do the things that the original SEA 493 didn't get finished back in 2003.

And in this model bill -- and we're talking to members of the Senate and the House about this -- it would establish targets in statute for the number of people to be served in home and community-based services.

In other words, the General Assembly would say to the State of Indiana: You have to increase the number of people being served in home and community-based services each year. And it

has to be a net increase over the previous year, or cumulative increase.

We're also proposing that any monies saved by investing in home and community-based services in reducing our expenditures on institutions, that money has to be reinvested, the same money, into home and community-based services. Indiana will never draw down the waiting list, will never reach every Hoosier who needs home and community-based services until there's a requirement that the dollars that are generated in savings, the public savings, are reinvested in people who need those services. So that's very, very important.

And we have a provision in our model bill, which will be interesting to run by legislators, which says after 2017 -- we're giving them some leeway here -- home and community-based services, through a Medicaid waiver in Indiana, should be an entitled service --

[Applause.]

-- if you're qualified for those services.

Now, a lot of people think that's wild and crazy, but if it's the smart thing to do, the most cost-effective thing to do, let's see, let's just quit, you know, I got to watch my language here. Let's just move ahead and do it instead of worrying about it all the time.

This legislation -- I'm just going to mention a few other things real quickly. We want to give area agencies on aging that enroll people in home and community-based waivers, we want to give them the ability to do presumptive eligibility. So if you need services through a Medicaid waiver and you're qualified, the eligibility process can happen on the spot instead of waiting six, eight, 12 months.

We want to beef up the pre-admission screening process so no one is sent to a nursing home when they should not be in a nursing home. It's crazy to send people from hospitals to nursing homes when that's an inappropriate placement. So we need a pre-admission screening system that keeps that from happening.

This legislation would also establish a state program to grow independent provider network. And so we would have -- will have the workforce we need for more home and community-based services, would require a state institution of higher learning to be a partner in helping to train and grow an independent provider network, and it would also establish a program for self-directed care in conjunction with growing an IP system.

So anyone who wants to self-direct his or her care can do so, and the State of Indiana would become the fiscal intermediary. So you don't have to worry about the business

side of doing self-directed care. And that is long, long, long overdue in this state.

I want to mention just two other things. Indiana currently has a so-called bed tax on nursing homes. The nursing home industry in the state officially calls it the quality assessment fee. We want to use a portion of those dollars to grow what are called green houses in Indiana and get away from the current law on nursing homes.

We think, over a period of five to 10 years, the State of Indiana should have a policy that if you have to go to an institution with substantial services, it shouldn't look like a nursing home. It shouldn't act like, smell like, taste like a nursing home. It should feel like your home. And that's something that we think would really, really work.

[Applause.]

And the last piece of this sweeping piece of legislation -- and this is on paper here. This is not all my imagination. But the last piece of this sweeping piece of legislation would be to establish an Office of Brain Injury Services. We're way past the time that people with brain injuries should be sent out of Indiana to get the ongoing therapies they need and could get in Indiana and stay at home and have cheaper, cheaper services and better services and they get to stay at home.

So those are all the features of our proposed legislation. We're kind of excited about this. And we're talking to Senator Becker and Representative Tyler in the House. And we think this is one of those things you just got to put it out there and let this puppy run and see what he'll do. Thank you, folks.

[Applause.]

>> NANCY GRIFFIN: Good afternoon, everyone. It's great to see so many people here at this conference. Isn't this a terrific conference?

[Applause.]

It's a privilege to serve as a member of the Council for People with Disabilities. I have a long association going back with the Council going back to 1890? 1990. Was the Council here in 1890? Well, anyway, it's been long.

I want to talk to you today about an issue that we're working on that I think affects a lot of people in this room, and that is our current Welfare system, the way people access Medicaid and food stamps and TANF services through our family resources offices. And I'd like to ask if people would be willing just to raise your hand if you've had dealings with the local division or family resource offices this year. How did it go?

[Laughter]

We all know. But we feel your pain. The good news is that the Governor's recognized that the system that we have is broken and it's not working and we've got to change it.

>> AUDIENCE MEMBER: About time!

>> NANCY GRIFFIN: About time is right. More good news is that the Administration has recognized that too many people are touching the application process for each individual, that we need to have more state-employed caseworkers, that they need to be working locally in offices and be available in numbers and trained in order to really provide timely and accurate service to people who are blind and eligible for these programs.

So the first thing that we're going to be working on is getting those state-employed caseworkers back.

Folks, let me tell you, this is not going to be easy and it's not going to happen overnight. The folks in Texas had a similar experiment in just three counties, not statewide but just three counties. They rolled back their program and closed it, canceled their contract after less than a year because it was such a mess. They're five years out and they're still short caseworkers because they have not been able to rebuild their system. This is going to be a real challenge, but it's something that we think is really critical.

First of all, state-employed caseworkers work for a

mission: To serve Hoosiers. That is not the reason that people work for private contractors. And we believe that's a critical difference, and that we really got to go back to that.

But the second thing is that we've got to have adequately trained and an adequate number of folks working in our local county offices so that when someone needs to apply, they get good service. And they get it today. Not in three weeks or two months. And quite frankly, that service has to be courteous. Unfortunately, my experience has been that that is not necessarily what people experience today. But if we can do this, by golly, in our license branch offices, we can do it in our Division of Family Resource offices.

[CHEERS AND APPLAUSE]

Another piece is what we think needs to be in this revised Welfare system is something that John mentioned, and that's the presumptive eligibility piece, where area agency on aging case managers could make -- presume, make a decision as to whether or not the person is or is not going to be eligible for Medicaid and on that basis determine whether or not that person could get services through a waiver under Medicaid or if they're not going to be Medicaid-eligible, get Choice services from the Choice Homecare program.

Now, I got to tell you, there are a lot of other states

that use presumptive eligibility. And for the most part, the error rate in those states, when area agency folks or other local community folks are doing presumptive eligibility, is less than 1%. Our current error rate is 13 to 15%. We can do better. And we know that we can do better.

But here's the other thing that's really important about presumptive eligibility, and I'll give you one example and that's the State of Kansas. In Kansas, the centers for independent living can do presumptive eligibility for Medicaid. Get that, huh?

[Applause.]

In Kansas, you can get services on the Medicaid waiver in 24 to 48 hours. How about that?

[Applause.]

Okay. Let's go there. Go Toto, right, John?

The last thing I want to talk to you about is something that I think will be a lot more controversial and a lot more difficult to achieve and I'm going to need your help. But this state spends an inordinant amount of your time, energy and frustration and a huge administrative burden by determining spenddown every month for folks on Medicaid.

How many of you have had to deal with spend down issues? Way too many. And the thing is: A lot of other states

determine spend down once a year. Imagine just the administrative savings from doing an annual spend down determination and what it would mean in the lives of people who are coping with significant illness, disability or aging issues when they're trying to make this system work every single month. It is way too hard on the folks that you're trying to serve. It is way too much to expect. And it's way too costly. It's part of why our system is broken. We're not being smart about how we're managing our eligibility determination.

And I think we have some clear opportunities right now. We know that we're going to have to change what we've got. We need to keep talking to our elected officials. We'll again be presenting legislative proposals that include some of these ideas. But we need to be talking to the Governor and to the Administration, as well. And I want to ask one more question, and that's: How many folks in this room are graduates of Partners in Policymaking? All right, you guys, let's go to work. Thank you.

>> STEVE McCAFFREY: I'm the President of Mental Health America. If you did attend Partners in Policymaking, you may have seen all of us before. Hopefully that's a good thing. And if you had, you would know that usually when John leads off, I don't really have time to talk. So this is a unique experience.

And I'm glad you're all here for it.

[Laughter]

Let me ask you a question. I don't want to be like the negative naysayer of this group because we all need to be positive and reach for the stars, but this is going to be a very, very difficult legislative session. You know, you probably know that the fight so far this session is whether or not we're going to go home early or really early. And the theme is really -- and really for a lot of us the theme is do no harm. Because we're concerned that with the budget that we have, that the only thing that can happen in that regard is bad.

As you probably saw in the press the Governor has put out, recognized revenues haven't been coming in the way they expected. He's trying to be fiscally responsible. He's asking for 10% reductions across-the-board in the agencies. And I'll give him credit. The agencies are working really hard in both DD and MI to make sure it doesn't affect services. But there's no way when you have reductions like they're going to be looking at -- and I'm afraid potentially bigger than that -- that it's not going to have an impact on all of you. And that's a concern.

And so what I think is going to happen this session is there's going to be a lot of cost cutting statements. And that

a lot of agencies are going to be put to the test to try to make that happen. And then during the session, a lot of legislators are going to hear from a lot of us -- and a lot of lobbyists that I would call more private interest lobbyists that are trying to make sure that their interests are represented. And it really could be a very, very nasty, nasty session. And I think, frankly, that the bad news is it could be something of a blood bath. And the good news is maybe we could just hold the fort. But the way to hold the fort is with your activism. And the fact that you participated in Partners, you certainly know how to do that.

But let me just ask you. You know, we heard in the plenary session this morning about the importance of voting from the Secretary of State and from our plenary speaker. How many people in this room vote every single election? Not just presidential, every single election. All right. Well that's great.

Let me ask you this. How many in this room -- and if you went to Partners, you know how important it is to communicate with your legislative official -- how many of you email your legislative official? How many email your official a couple times during the session, at least, or more?

How many have taken it to the next step and called your

legislative official?

How many have met with your legislator? That is great. Well, obviously you're doing something right, because that's what we need. And we're going to need it more than ever this session. This session, I think, could be one of the most difficult of my tenure.

In mental health, there's going to be a concern about cuts. There's going to be concern about cuts in Medicaid. And one of the areas that I have spoken to you all before is about access to mental health medications. And for those of you -- anybody willing to admit that they have a psychiatric disorder, mental health disorder? For those of you with those disorders, you know that access to appropriate medication is key to your success. And we passed a law, it's one of the best in the country, that says you should have open and appropriate access to mental health medications if you're on Medicaid. And there's a concern that that will be at risk with these type of budgetary cuts.

Another thing that we're looking at is the issue of smoking. Now, I'm not going to ask you how many people in here smoke. But we do know that within the disability community, that there's a higher incidence of smoking. And we know that in the area of mental health, the life span of a person with

serious mental illness is on average 25 years shorter than the individual without a serious mental illness. And one of the big reasons is smoking.

And so one of the things that we're going to do is ask that as the state moves to -- with some success within their institutions with smoking cessation, we're going to ask that the same providers, the division of mental health and addiction institute the same kind of smoking cessation policies. There should be smoke-free premises. You shouldn't have to be stuck with second-hand smoke that you don't want. And for those of us who do smoke, we need to have cessation programs that can assist us in getting off what is very much one of the strongest addictions that exist in our society.

You know, there's mention at the plenary session of healthcare reform. And I know you're going to have more discussion on that. But I won't be there, so I'm going to mention a little bit of it now.

I think we all know that what's been talked about, there is a lot of stuff that matters and there's a lot of stuff that doesn't matter. But what does matter is that all the bills that are being discussed focus on expanding coverage to the uninsured. That's a good thing.

The other thing that all the bills talk about is no

pre-existing conditions. And that's a great thing.

And from our perspective, all of the bills have mental health parity and parity for substance abuse in all the bills. And there's discussion about that in the morning session. So for those that aren't aware, mental health parity says that you should get coverage for mental health conditions the same way -- not less -- the same way as you do physical conditions. That means the copay should be the same.

[Applause.]

That means the deductible should be the same. The length of stays in inpatient settings should be the same. The number of outpatient visits should be the same. There should be no discrimination when it comes to psychiatric disorders because they are, in fact, medical.

When I talked to you before, I've told you that in the State of Indiana, we passed mental health parity. And some of you are confused because you didn't feel like you had it. But the reason is that because in state law, all we can do is affect those insurance policies that are affected by state law, which roughly is about a third of the policies. But as was suggested this morning, the really neat thing that happened last year was that Congress finally passed -- and the President signed -- the Mental Health Parity Act for everyone, at the state and federal

level.

And the question was asked earlier: When does that go into effect? Well, the statute says that the effective date is January of 2010.

And since its passage, there's been discussion about promulgating rules and regulations to enforce mental health parity. In fact, there's been a comment period. And we at Mental Health America have weighed in on that and tried to comment how we can make sure that it's implemented in an effective way.

I'm not sure, frankly, if they're going to be able to get it implemented by January 2010 because they haven't got the rules promulgated yet. But they are working on it. So it is imminent.

So within months, we will have no discrimination in terms of insurance coverage between mental health and physical health. And if we pass health care reform, that will be an integral piece of healthcare reform. That is the best thing that could ever happen in our movement. It will be the most important thing I have ever seen.

[Applause.]

But then it comes to the states. After they pass healthcare reform, it's going to come back to the states for

implementation. And the states are going to be responsible for deciding how it's going to be implemented.

And as was mentioned in the plenary this morning, they're going to talk about entitlement programs and Medicaid expansion. That happens at the state level. So that's where we get back to what you learned at Partners and your calls and your letters and your Emails and your votes. That will happen here.

If you're interested, we'll keep you apprised of that. Go to www.mhai.net. And there is an opportunity that you can sign on and receive action alerts. And if you do that, we'll keep you posted on what's going on with mental health parity, healthcare reform, access to medications. We'll let you know when it's time to call or write your legislator. And if you do so, it would be very, very appreciated. Thank you so much.

[Applause.]

>> KIM DODSON: Good afternoon, everybody. I first want to thank Suellen, Christine and Steve for putting together this wonderful conference. I look forward to this every year.

[Applause.]

I also want to thank John and Steve for getting John and me to talk on the panel today. We know when they talk first we don't get a chance to talk a lot, so we appreciate the opportunity to talk.

I'm going to pick up on a little bit of what Steve started, and that is just kind of talking about the forecast for the upcoming legislative session. This is a short session. We're going to get started on January 5th. We actually get started tomorrow with Organization Day, which I think everybody else is like I can't believe it's time to be getting this conversation. But we come together on January 5th for the legislative session. By statute, it has to be over with by March 14th. There is a lot of rumors out there that we may actually be done by Valentine's Day. I actually don't believe that that's going to happen. But it's always a possibility.

There is going to be some key areas of conversation this session. And I think the big drivers of conversation this session is that everybody is already focused on the November elections of next year. Those elections are going to detail who represents the majority in the House and I think the Republicans are trying very hard to get majority back in the House of Representatives. The Democrats, of course, want to hang onto that.

The reason why next year that is so valuable is that these will be the leaders that will be putting together the districts, the new legislative districts. And so of course each person wants to be in the majority so that those districts can lean in

their favor. So that's why those elections are so important.

The conversations around the constitutional amendment regarding property tax caps, this is going to drive a lot of the conversation this session, as well. Legislators are hearing all over the state that this is a big issue. And this is the year that we really have to act on it.

Lobbying reform efforts. If you guys read the paper this Sunday, we are getting hit very hard about what lobbyists do. And so there is a big push this year to see some legislative reform efforts. And in my opinion, I think a lot of that is again leading up to the November elections, that legislators want people to know that their votes cannot be bought. They listen to their constituents. And that those special interest groups are not as important as what the paper says.

So these are kind of the big issues, kind of laying the groundwork for this session.

Nancy talked about this Medicaid Modernization Project. This is going to be another key area of conversation this session. I think everybody is finally in agreement that the mistake that -- that they made a mistake with the contract with IBM. I think everybody is now looking at how it can be fixed and are now looking to advocates to give suggestions on how to best fix the system. So that will be a key area.

This summer we had some Legislative Study Commissions. They got started kind of late with the Special Session. Most of them held two or three meetings. In the area of developmental disabilities, we have two areas that we're really going to be focusing on. One is employment.

You know, when you hear about employment issues, you're hearing in the State of Indiana that we have this 10% unemployment rate. And to me, I'm not so focused on the 10% unemployment rate for the general population, I'm more focused on the 88% unemployment rate for people with developmental disabilities. I think we really need to concentrate on that.

So one of the things that the DD Commission really concentrated on this year is employment efforts to increase -- to double the employment rate of people with developmental disabilities to 44% by the year 2015. And so we're going to start laying the foundation for that for this year and talking to people and really engaging the business community on what more can be done to see that rate of employment increase.

Another one is we have far too many people with developmental disabilities getting involved in the criminal justice system. And so I am wanting to learn from my friends in the mental health community on their diversion programs to see what programs we can set up to help people with disabilities as

they get involved with the criminal justice system.

Now, on the national front, we are of course very involved with the healthcare reform efforts. You're going to hear tomorrow from Liz Savage, who is an expert in the field, and I think her panel discussion will be very important for all of you to hear.

Other issues that I know are going to come up is education issues. Any of you who have children in special education understand that we are under a new Administration. They have a lot of different ideas about how children's special education needs to be taught, who needs to be teaching them. And so we will be very involved and interested to see what kind of things that they propose this year and how they affect the special education community.

Transportation, this mass transit conversation, we are going to have a watchful eye on, as well, so that people with developmental disabilities can benefit from the mass transit, any type of organization that happens there.

Accessible voting. We want to make sure that everybody has access to voting machines when it comes to voting, not only next November but May and the primary, as well. So we'll be watching that kind of stuff.

Steve talked about how it's important for you guys to get

involved. Many of you already are. We need you to continue that. There already have been cuts, there are going to be more cuts. I think it was John that referenced that a lot of times when the state has been at its most budget crisis is where creative thoughts have really come together and good things have happened. I think that's going to be the case for the next year.

We have a lot of opportunities to work with the state. We have been invited to the table to kind of brainstorm. We are very, very fortunate, at least in the developmental disability community, that we have good leadership in our division of the state. We look forward to working with them. And fortunately they always ask for our opinion -- they don't always like it, but the compromise that comes out is always better than one person's idea. So we look forward to continuing that.

Again, get involved, stay involved. This session will be a great one to build your relationship with your legislators. Again, there are so many new people that came in in 2008. They are looking at issues to champion for this coming year. They know that they need to build their résumé for their election report cards and their election materials. Make that issue be yours. Make that issue be ours.

If you have any questions or concerns, you know how to get

ahold of all of us through the Governor's Planning Council. Just, please, look to us for information. But we really depend on you to build those relationships and to really make that personal contact with legislators.

I think at this time we're going to just kind of open up the microphones, if there's any questions, and then if there's any comments the rest of the panel wants to make. Thank you.

[Applause.]

>> Marvin: Our son is in the developmentally disabled waiver program. Several disabilities and chronic illnesses, including a psychiatric condition. And because of the multiple conditions, he has been told by multiple doctors that he has to live in a one-unit arrangement, the provider agency in our district has tried him in a setting with roommates.

Well, the district officials are cutting the budget and saying that's our problem that he can't live in a facility with multiple house mates. They ignore professional -- I'm talking about psychiatrists and primary care physician opinions that say "that's your fault, family."

So I want you people to tell my wife and me specifically what you would say to the high district officials that are saying that to us. I need a specific answer.

>> Marvin, you and I have spoken a little bit about this

and sent some emails. There are some changes happening in the budget area with people. And this is where we need to be creative. The house mate issue has been one that has been looked to as ways of saving money. I think your area, we need to talk with people more specifically about all of care issues.

I think Peter's here. Peter would be very interested in trying to work one-on-one with you on trying to fix your situation to make it better.

>> Marvin: We're open to that. But that message isn't getting through to the district service coordinator and district manager who shrug their shoulders and say, "Well that's your issue. Why don't you go to the psychiatrist or the doctor to help fund his housing?"

>> I think that needs a little bit more hands-on than maybe what we had before. I'll get with you a little bit. Make sure we talk with Peter, too, to see what we can do more.

>> Marvin: One other thing, Kim. I work with two parent coalitions in our district. And there are other parents who have children but different disabilities that will not work in a multiple-housing arrangement. We'll have to band together and will do that if we don't get someone to listen to us.

>> There's some flexibility there that I think we need to talk about individually.

>> I have a question. With care and Medicaid situation budget, I'm afraid that we're going to be losing more agencies to take care of us. And one of the biggest problems is paying the workers, the CNAs. I mean, they don't get hardly anything and they're out there like 24 hours 7 days a week. And they're getting burned out. They always say "it's the budget, it's the budget." And so I want to know: Is this going to affect people with disabilities' inhome care?

>> NANCY GRIFFIN: You raise a very important question. You're right. They often can't afford to pay anymore. But what John is talking about earlier, an independent provider network actually creates an opportunity to have folks work independently outside of the agency and be compensated at a higher rate.

In other states, I think built wide, broad independent provider networks, those networks have actually been able to lobby to raise the tide for all workers. And it's about building that kind of consensus and building strength between the folks who serve people with disabilities and the folks with disabilities and our families. And we have to stand up for those people.

Another huge issue that we have right now in Indiana is many homecare workers are not getting anything for their travel time or for mileage. And that makes it very difficult for folks

to get especially out into rural areas.

But the other piece that's huge and that could be very much affected by what's going on in the national health care debate is the fact that many homecare workers have no access to healthcare for themselves and their families. And that is a huge opportunity we need to keep our eyes on.

>> I have a question. The spend down. Does everybody know that gets disability in 2010, we will not get a cost of living adjustment? However, when you go and get re-certified, whatever expenses you had before, I have Medicare Part D, and I have to make a copayment and various other things. Why are they going to raise how much your spend down is if you're not getting more money? But you're paying more in copayments. At one time your copayment may have been \$2 or whatever depending upon what you're getting. Now it has gone up. If you get a name brand, it's higher. But they have not kept the spend down where it goes down. What's actually happening is that they are raising how much we spend on spend down and we're not going to get anymore money. Instead, we are spending more for living conditions, transportation, whatever you might need, some things that are not covered by Medicare or Medicaid. It might be something that you personally need that may make it better for you to get around. And I want to know why they are going up and

we're not getting any more money. I can't understand why no one ever addressed that issue.

>> NANCY GRIFFIN: You're absolutely right. It's very unfair. But again this goes back to the national debate on healthcare. One of the things that is currently in the House Bill is significant expansion of Part D under Medicare that would cover much more of the costs of your drugs. We need to pass substantial legislation that addresses healthcare costs and access for everyone at the federal level.

Your specific question about spend down, it's like yin and yang, we can have different decisions without looking at the impact on individuals. I wish I could give you a better answer. But we've got to keep after that healthcare.

>> Just my personal opinion, but I have to say it, because I think about it all the time, in a way, I really believe half of the people that are doing that work don't seem to really know what they are doing. Because one person say one thing, then you call someone else and say something. It's like there's not a set-in-stone system. It's just as you go, they make up a rule to fit you in some kind of way. But it always come out that you're the one that pays the most.

>> Why cut Medicare down? Because Medicare. Do not cut Medicare out.

>> STEVE McCAFFREY: Anyone want to comment on Medicare?

>> NANCY GRIFFIN: We just need to strengthen it.

>> STEVE McCAFFREY: Okay. I got a question back in the back for you.

>> I do have one comment about the last person about spend downs and Medicaid. I do agree with that with regard to healthcare bill. The one thing is when it comes down to Medicaid and spend downs, the more money you have, the higher the spend downs go. Because I wanted to send a letter to the editor for the Indianapolis Star to encourage the Senators regarding the vote for the healthcare bill, to try and keep the trigger out of the being approved. So that way we could keep the healthcare bill clear so that way we could keep the public option going in the federal legislation.

And one thing is that I'm looking at the whole deal on it is if we can get this, the public option going, that may help out with eliminating the spend downs under the Medicaid if I understand correctly. If I am wrong, somebody correct me.

>> NANCY GRIFFIN: Right on. Right on. Hang on just a minute for the mic, please.

>> I don't need a mic, I got a big mouth. I have a question about Medicare. I was a home healthcare provider until I quit my agency because they didn't want me to -- I was

supposed to go in and do my hours and then leave. But that's not my question. My question is: Why do the people that are receiving Medicare have to go to a different doctor for every single thing?

Example. One gentleman I took care of, 11 doctors. He had to go in to a podiatrist every two months to get his toenails clipped. \$300 Medicare was billed. He was going in for laser surgery on his eyes. The man had Macular Degeneration. The laser surgery wasn't doing any good, but he had mental health issues. He didn't understand. He just did what his doctors told him to do. If he was having a bladder issue, he had to go to a urologist. If I have a bladder problem, I go to my doctor, they take a urine sample and they give me antibiotics. He was going to 11 different doctors. That's a lot of money. Why does Medicare require that you go to a specialist? Think of the money the health care system would save if they cut that out.

>> NANCY GRIFFIN: Well, what you're getting to is the fact that we still have a fee-for-service system in this country. We're not talking about quality outcomes and paying doctors and hospitals and other healthcare providers for good health outcomes. We pay them for each individual service. And so that's the way the system is built, that's where the incentives are. And unfortunately that's why our healthcare system costs

so much today. It's a big change we have to make.

>> Is that going to be part of the --

>> STEVE McCAFFREY: Good news is in health care reform, they are looking at coordination of services and having a medical home that will include all the different kinds of services, including psychiatric care. That's one of the big things that's in all of the bills. So it's very likely that that will happen.

>> Okay. And you were talking about no pre-existing conditions? I don't have healthcare. When I was a home healthcare service whatever, I don't know what I was, worker, thank you, I quit my agency. I couldn't walk out on my clients, especially this guy. I mean, he was elderly. He was a widow. He had a son living with him that had serious mental deficiencies. They needed help. And it was on my own time. But I was being penalized through my agency. But I wasn't getting the mileage, the travel, no healthcare.

So in this healthcare reform for noninsured people, everything that I have is pre-existing.

>> KIM DODSON: I'm sorry. Could you pass the microphone?

>> So everything that I have is pre-existing. Am I going to be excluded from this healthcare reform?

>> STEVE McCAFFREY: No. I mean, it hasn't passed. And we

haven't seen the final version. But every version in both the House and the Senate eliminates the pre-existing condition clause. So you should be okay.

Let me get this woman over here.

>> I just wanted to follow-up on one of my table mate was speaking about earlier. His concern was concerning housing of actually his son who is needing to live in a multiple dwelling opposed to in his own home.

One of the problems service providers are running into is HUD requires that certain regulations for their establishments and therefore service providers are running into complications, especially with the developmental disability community and the mental health community, in being able to house those consumers under those requirements.

So I have suggested that he might want to also be working with ISHTA, Indiana community home ... and HUD on this issue as well as working with Kim and maybe others of those that have been in this panel in dealing with this issue. Because I know from one of the organizations I'm involved with, this was a big issue that they were having in an establishment that they had built some apartments, but they weren't able to house clients of theirs in there because they could not get more than one or two of them to live in a dwelling together.

>> STEVE McCaffrey: Okay, great. We have probably time for one or two more questions.

>> Mine is not really a question. It's an experience that we had this last six months. I'm on Medicaid. I only have to use it for special things like my dental and that, otherwise I have AARP and my Medicare.

But the first of the year I needed surgery on my mouth. And there was no way that they would add up my spend down to total the amount that I needed. So my husband, he's a farm hand, he says, he started calling the governor's office every day. He called the governor's office. He called the family and children services. And they kept saying I didn't have a spend down.

Well, we have a social worker in Vincennes help us get the spend down in. We knew it was getting. We had the faxes that they received it. But they didn't credit us with any of it. So there we had six months.

So after he started calling every day, they started looking it up. They found some in Fort Wayne. They found some in Marion. They found some somewhere else, another town, I'm not sure which. But they started finding out that we had spend down. And it had been turned down since the very first of the year. One month they gave me one day to use my spend down.

They credited it for one day. But in the end we ended up getting our spend down, but it took us months to do it and to prove that it was there.

So I mean if I can't do it and I worked in the system, how are everybody out there that does not have access to the computer, who do not have access to help?

I went to the center in Davis County, and they told me they didn't even know how to access the Indianapolis phone number. So how much help is that? So I don't know. The system really has to be changed so that everybody out there that needs it can get help. Thank you.

>> JOHN CARDWELL: Thank you for your comment. We have one more person over there. But let me say real quickly many of the things Nancy was talking about go to what you're raising. And we are specifically advocating that every county office regain the capacity for comprehensive case work services. And that every county office has a staff that is completely competent in terms of dealing with all the issues that go through Medicaid. In other words, all the services that should be handled through the local division of family resources' office so you won't have to deal with that kind of problem.

And part of what we're advocating is a new computer system that's county-based, smart, simple technology. And you have the

right, as a client or anyone else as a client, have the right to see what's in your records so if there's a problem there, it can be flagged by you and you don't have to go through months and months of waiting for someone out of the county to make a decision who doesn't know about your case. Do we have time for one more question?

>> STEVE McCAFFREY: And I know that John has said that he's willing to stay all day if he has to to answer questions one-on-one.

[Laughter]

>> This is Victor. The governor and I want you to talk to Mike and my brother's daughter, Morgan, because he has an email. A job to my sister's went to Washington, D.C. and I called my sister and Barbara, you are my wife, talked to my family and I have three sisters and brothers. You must email my systems all at Stengal and here's the address. And then that's it. And I want to be anybody to like me for tips and Victor.

>> I remember the first time -- Bush, but I ain't now, the governor of the state, first time I went to Washington state.

>> STEVE McCAFFREY: Thank you.

>> STEVE TILDEN: We're out of time now. I want to make a general statement that I think runs through all the presenters here and that is that we have hard times. We can look at it as

a glass half full or half empty. But we are the ones here in the audience, the people that represent other people, that are involved in this that need to carry this further to stay in contact with the folks at our table here and with the Partners' folks and to contact their legislators. That's the one main theme that comes through this. So I want to ask everybody to give a big round of applause to Kim and Nancy and John and Steve.

* * * * *

This is being provided in a rough-draft format.

Communication Access Realtime Translation (CART) is provided in Order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings.

* * * * *